

# Informed consent in the intensive care unit: the experiences and expectations of patients and their families

Lucy J Modra, Graeme K Hart, Andrew Hilton and Sandra Moore

The practice of obtaining informed consent for invasive procedures (procedural consent) is a controversial area of intensive care medicine. Once considered unnecessary, there is increasing interest in obtaining informed consent before all non-urgent intensive care unit procedures.<sup>1-3</sup> In Australia, the College of Intensive Care Medicine recommends obtaining informed consent before all non-urgent procedures.<sup>4</sup> Although there are no local data published, audits from Europe and the United States show marked variation in procedural consent rates.<sup>1,2,5,6</sup> This suggests that introducing routine procedural consent would represent a significant change in current practice.<sup>7</sup>

Informed consent is defined as a patient's autonomous authorisation or refusal of a proposed intervention, based on an understanding of relevant options and their potential consequences.<sup>8</sup> Informed consent is intended to promote patient autonomy by involving patients in their health care decisions. Several studies question the level of understanding or autonomy that patients achieve in practice.<sup>9-12</sup> Nonetheless, obtaining informed consent is a well accepted practice in many areas of medicine, and is a mandatory component of the World Health Organization's Surgical Safety Checklist.<sup>13</sup>

There are significant barriers to obtaining informed consent from ICU patients. Most ICU patients are not competent to consent, due to illness or sedation; therefore, consent is obtained from surrogate decisionmakers.<sup>2</sup> As ICU patients often need multiple procedures, the consent process may be burdensome for patients, families and clinicians, or distract them from "bigger-picture" discussions. Against these concerns, proponents of procedural consent point to improved communication about ICU care, improved trust between patients, families and clinicians, and increased medicolegal protection for ICU clinicians performing procedures.<sup>2,3,14</sup>

ICU patients and their relatives are key stakeholders in this debate, but there is little research into their expectations and preferences. Clark reported a positive correlation between patients' experiences of informed consent in the ICU and their satisfaction with care.<sup>15</sup> A survey of emergency department patients found that desire for medical information and involvement in decision making did not decrease as acuity of illness increased.<sup>16</sup> These findings suggest that ICU patients and families may support procedural consent, but they do not consider the issue directly.

## ABSTRACT

**Objective:** To describe the awareness of intensive care unit patients and their next of kin (NoK) about invasive procedures and their expectations of informed consent for procedures in the ICU.

**Design and setting:** A written survey of patients and their NoK in a tertiary, university-affiliated ICU, using multiple-choice questions, Likert scales and comments to generate semiquantitative and qualitative data.

**Participants:** Fifty-one ICU patients and 69 NoK completed the survey. Inclusion criteria were unplanned ICU admission, ICU length-of-stay > 24 hours, English speaking and competent to consent to participate.

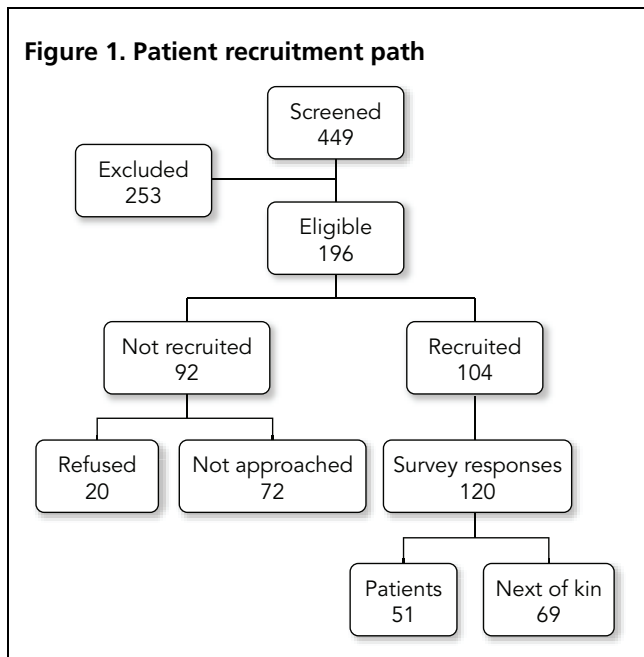
**Main outcome measures:** Proportion of procedures respondents were aware had occurred during ICU admission; satisfaction with information received; preferred method of receiving information and giving consent; and expectations of when procedural consent is required.

**Results:** Patients and NoK were unaware of many procedures performed during their admission. Respondents correctly identified 49% (95% CI, 45%–53%) of procedures performed during the patient's ICU admission. Despite this, most patients (80%; 95% CI, 69%–91%) and NoK (94%; 95% CI, 89%–100%) were satisfied with information provided about procedures. Over half of respondents (55%; 95% CI, 46%–64%) only expected consent for procedures that were "risky or not routine". About one-quarter (27%; 95% CI, 23%–31%) expected to give consent before every procedure and 15% (95% CI, 11%–18%) expected no procedural consent process. Patients and NoK strongly preferred a verbal rather than written consent process.

**Conclusions:** Our results suggest there is a limited degree of support for routine procedural consent from ICU patients and their NoK.

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Our study aims to address this gap, asking, "do ICU patients and their relatives want an informed consent process for procedures?" Specifically, we aim to describe patients' and relatives' awareness of procedures, the types of procedures for which they expect informed consent, and their preferred consent process.



## Methods

### Design

We conducted a written survey of patients and/or their next of kin (NoK), including multiple-choice questions, Likert scales and comments, generating semiquantitative and qualitative data (see Appendix online at [cicm.org.au/journal.php](http://cicm.org.au/journal.php)).

### Objectives

Our study aimed to answer the following prospectively defined questions:

- Are ICU patients and/or their NoK aware of the procedures undertaken during the patient's admission to the ICU?
- Are patients and families satisfied with the information provided about procedures?
- How do patients and families prefer to receive information about procedures?
- Do patients and families expect informed consent for procedures performed in the ICU?
- Do ICU patients and NoK have different expectations for informed consent?

### Sites and participants

The study site was the Austin Intensive Care Unit, an 18-bed Melbourne tertiary referral ICU with about 2200 admissions per year. During the study period, ICU clinicians obtained formal written consent for percutaneous tracheostomies, bronchoscopies and gastrointestinal endoscopy. Formal consent was not obtained for other

procedures such as vascular access, endotracheal intubation or diagnostic or therapeutic aspirates. Whenever possible, procedures and their rationales were explained to patients and/or their NoK.

Patients and their NoK (as nominated in the medical record) with an unplanned admission to the ICU were prospectively recruited to participate. Potential participants were approached at least 24 hours after ICU admission, to ensure procedures had occurred before the survey was completed. Patients with planned postoperative ICU admissions were excluded as they have most procedures performed in the operating theatre. Other exclusion criteria included the patient being non-English-speaking, the admission being less than 24 hours, and the patient not being competent to consent. If the patient was competent to participate, both patient and NoK were approached; otherwise, only the NoK was approached.

### Ethical considerations

Ethics approval was obtained from the Austin Health Human Research Ethics Committee (H2012/04680). Informed written consent was obtained from all participants before they completed the survey.

### Study period

The study was undertaken over 13 weeks in three non-consecutive periods of 2012: 11 July to 2 August, 13 August to 6 September, and 25 September to 11 November.

### Data collection

A research assistant (LM or SM) invited patients and/or their NoK to complete the survey. Staff members were advised not to help participants with the survey, but to answer any questions arising after its completion. Participants returned surveys to a closed box within the ICU. At the time of recruitment, the patient's nurse completed a checklist of procedures performed during the patient's ICU admission.

### Data analysis

Descriptive statistics are presented as means with standard deviation or medians with interquartile ranges, depending on the data distribution. Categorical data are presented as raw numbers and percentages with confidence intervals. In cases where data were missing, no assumptions were made about missing data. Data analysis was performed using Stata, version 12 (StataCorp). Comparisons of proportions were conducted with the  $\chi^2$  test or the Fisher exact test, depending on data distribution. For all statistical analyses, a two-sided  $P < 0.05$  was taken to indicate statistical significance. Qualitative data were analysed and grouped by themes.

**Table 1. Demographic data of patient participants v next-of-kin participants**

Variable	Patients	Next of kin
Mean age, years (SD)	58 (19.7)	51.4 (13.5)
Age range, years	24–86	23–86
Women (%)	22 (43%)	35 (51%)

## Results

### Participants

In the study period, 449 patients were admitted, of whom 196 were eligible to participate, and 253 patients were excluded for the following reasons:

- 165 were planned postoperative ICU admissions
- 79 were ICU admissions of less than 24 hours
- three patients and their NoK were non-English-speaking
- six were not competent to consent and had no NoK recorded.

Of the 196 eligible patients, 104 (53%) were recruited, with the patient, their NoK or both completing the survey. This yielded 120 survey responses, with 51 patient responses and 69 NoK responses (Figure 1).

### Demographic data

NoK participants had a lower mean age than patient participants ( $P=0.03$ ), with no difference in sex distribution between the two groups ( $P=0.41$ ) (Table 1). Comparing patient participants with eligible non-participants, participants had a lower mean Acute Physiology and Chronic Health Evaluation (APACHE) III score, compared with non-participants ( $P=0.03$ ) (Table 2). There was no difference in age ( $P=0.2$ ) or sex ( $P=0.69$ ) of these two groups.

### Awareness of procedures performed

Respondents were asked to identify procedures they had had during their ICU admission from a list of 14 common ICU procedures. The list included the technical name of procedure (eg, "vascath"), and a brief lay description (eg, "line for kidney machine"). Participants could select the option, "I am unsure which procedures were performed during my admission to the ICU" in addition to any procedures identified.

**Table 2. Demographic and disease severity data of participants v eligible non-participants**

Variable	Participants	Non-participants
Mean age, years (SD)	58.2 (17.9)	61.8 (20.9)
Age range, years	19–91	16–94
Women (%)	46 (44%)	36 (39%)
Mean APACHE III score (SD)	58.9 (25.8)	67 (24.8)

APACHE = Acute Physiology and Chronic Health Evaluation.

Respondents were unaware of many procedures performed during the patient's ICU admission. NoK respondents were aware of more procedures than patient respondents ( $P=0.01$ ). Patients correctly identified 97 of 230 procedures performed (42%; 95% CI, 36%–49%). NoK respondents were aware of 210 of 397 procedures performed (53%; 95% CI, 48%–58%) (Table 3). Patients and NoK incorrectly identified 29 additional procedures that were not performed.

**Table 3. Awareness of procedures: number of times performed and correctly identified,  $n$  (%)**

Procedure	Patients		Next of kin	
	Performed	Identified	Performed	Identified
Vascular access*	142	61 (43%)	210	110 (52%)
Bronchoscopy, gastroscopy	11	6 (55%)	13	5 (38%)
Endotracheal intubation	13	4 (31%)	43	25 (58%)
Other†	64	26 (41%)	131	70 (53%)
<b>Total</b>	<b>230</b>	<b>97 (42%)</b>	<b>397</b>	<b>210 (53%)</b>

\* Central venous catheter, arterial line, pulmonary artery catheter, peripheral intravenous cannula. † Intercostal catheter, lumbar puncture, abdominal paracentesis, indwelling urinary catheter, rectal tube, nasogastric tube.

**Table 4. Satisfaction with information on procedures,  $n$  (%)**

Level of agreement	Enough information		Easy to understand	
	Patients	NoK	Patients	NoK
Strongly agree	9 (18%)	25 (36%)	8 (16%)	24 (35%)
Agree	31 (62%)	40 (58%)	36 (70%)	44 (64%)
Disagree/strongly disagree	4 (8%)	2 (3%)	3 (6%)	1 (1%)
Don't know	6 (12%)	2 (3%)	4 (8%)	0 (0%)
<b>Total</b>	<b>50</b>	<b>69</b>	<b>51</b>	<b>69</b>

NoK = next of kin.

**Table 5. Preferred method of receiving information, n (%)**

Method	Patients	Next of kin	Combined
Written	6 (12%)	5 (7%)	11 (9%)
Verbal	31 (61%)	37 (54%)	68 (57%)
Written and verbal	12 (23%)	25 (37%)	37 (31%)
None/other	2 (4%)	1 (2%)	3 (3%)
<b>Total</b>	<b>51</b>	<b>68</b>	<b>119</b>

**Table 6. Preferred method of giving consent, n (%)**

Method	Patients	Next of kin	Combined
Written	14 (28%)	20 (30%)	34 (29%)
Verbal	30 (60%)	39 (58%)	69 (59%)
None	1 (2%)	5 (7%)	6 (5%)
Other	5 (10%)	3 (5%)	8 (7%)
<b>Total</b>	<b>50</b>	<b>67</b>	<b>117</b>

Twenty-one patients (41%; 95% CI, 0.28%–0.55%) and 16 NoK (0.23%; 95% CI, 0.13%–0.33%) selected “I am unsure which procedures I had during my ICU admission.” Patients were more likely than NoK to select this option ( $P=0.03$ ).

**Satisfaction with information**

Participants were asked to rate their satisfaction with the information provided and its comprehensibility on 4-point Likert scales.

Despite being unaware of many procedures, most patients and NoK were satisfied with the information they received about them. Eighty per cent of patients (95% CI,

69%–91%) and 94% of NoK (95% CI, 89%–100%) agreed or strongly agreed that they received enough information about procedures; 86% of patients and 99% of NoK agreed or strongly agreed that this information was easy to understand.

There was a statistically significant difference between patient-reported satisfaction and NoK-reported satisfaction for amount of information received ( $P=0.03$ ) and its comprehensibility ( $P=0.01$ ). NoK were more likely to strongly agree that they received enough information and that the information was easy to understand (Table 4).

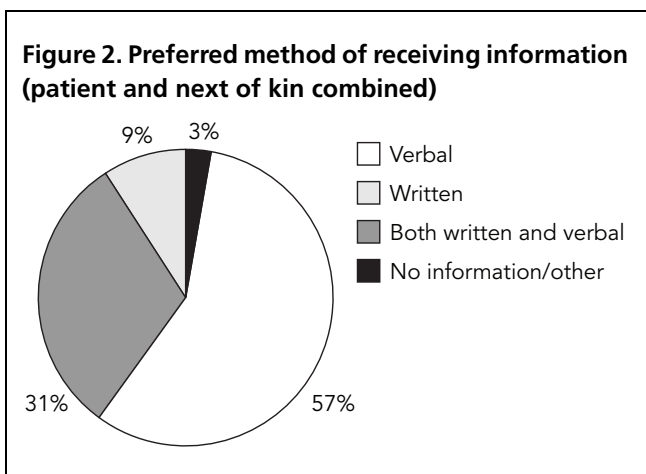
**Preferred method for information and consent**

Both patients and NoK responders preferred verbal rather than written information about procedures; 57% of all respondents (95% CI, 48%–66%) preferred to receive information about procedures verbally, and 31% (95% CI, 18%–34%) preferred both verbal and written information. There were no significant differences between patients and NoK in preferred method of receiving information ( $P=0.36$ ) or giving consent ( $P=0.43$ ) (Table 5 and Figure 2). For giving consent or formally authorising a procedure, 59% of respondents (95% CI, 50%–69%) preferred a verbal process and 29% (95% CI, 21%–37%) preferred a written process (Table 6 and Figure 3).

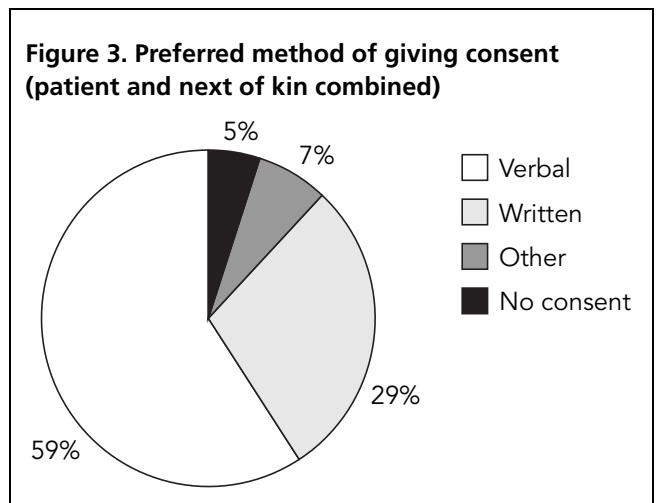
**Expectations of procedural consent**

All respondents were asked whether they expected informed consent for ICU procedures. Patients were asked about personal consent (if competent) and proxy consent from NoK if they were unable to consent themselves. NoK respondents were asked about their expectations of proxy consent: 55% of all respondents (95% CI, 46%–64%) expected consent only for procedures that were “risky or not routine”; 27% (95% CI, 23%–31%) expected consent

**Figure 2. Preferred method of receiving information (patient and next of kin combined)**



**Figure 3. Preferred method of giving consent (patient and next of kin combined)**



**Table 7. Expectations of procedural consent, n (%)**

Procedure*	Consent type			
	Patient	Patient proxy <sup>†</sup>	NoK proxy	Patient + NoK
All	15 (30%)	9 (19%)	16 (24%)	31 (27%)
Risky/non-routine	25 (50%)	27 (57%)	39 (59%)	64 (55%)
No consent <sup>‡</sup>	10 (20%)	8 (17%)	7 (11%)	17 (15%)
Specific	0 (0%)	3 (6%)	4 (6%)	4 (3%)
<b>Total</b>	<b>50</b>	<b>47</b>	<b>66</b>	<b>116</b>

NoK = next of kin. \* "Would you expect to be asked for your consent before ...".  
<sup>†</sup> Percentages do not add to 100 due to rounding. <sup>‡</sup> "I don't expect to be asked for consent if the procedure is necessary for my/my relative's treatment."

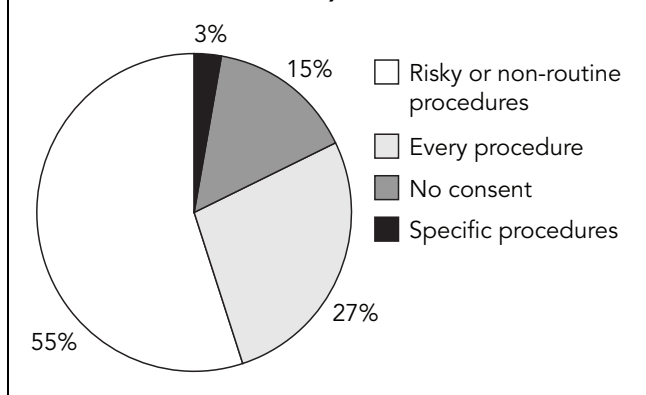
before every procedure and 15% (95% CI, 11%–18%) did not expect informed consent for procedures (Table 7 and Figure 4).

Patients and NoK had similar expectations of procedural consent, with no significant difference in the distribution of responses between the two groups ( $P=0.15$ ). There was also no difference in patients' expectations of consent if this was obtained from a competent patient, or from the NoK if the patient was not competent to consent ( $P=0.22$ ).

Three patients commented that they did not expect or desire procedural consent. One commented, "If [the procedure]'s necessary, just do it." Another wrote, "I totally trust the nurses and doctors. They know what's right for me."

Three NoK respondents were concerned that procedural consent would interfere with their relative's care. One explained, "I think that doctors should be able to make decisions on patient's health without wasting valuable time looking for relatives and discussing it with them. Most relatives unless working in health-related jobs are only guessing what the right thing is to do." Another commented that, "Only when very risky do I want to give

**Figure 4. Expectation of procedural consent (patient and next of kin combined)**



consent. Any method is applicable, however if obtaining consent jeopardises the patient, then I waive consent".

**Themes arising from comments**

*Competence and implied consent in emergencies*

Five patients noted that they were not competent to make decisions about procedures during their admission. One patient commented that they were not "... conscious enough when lines went in". Another explained, "It's a bit different with neurological problems because you just fall in a heap and they do what they have to do. If it was a hysterectomy or something you could logically make a decision. But with neurological stuff you can't think or talk or anything".

Six respondents commented specifically on implied consent for emergency procedures.

*Relatives as surrogate decisionmakers*

Three patients commented on the importance of relatives acting as surrogate decisionmakers. In contrast, one patient was concerned about the potential burden of procedural consent for her elderly husband: "I only have my husband, I wouldn't want him bothered". Two NoK noted the difficulty of obtaining proxy consent when they are not in the hospital. For example, "If my son needed some procedure and I couldn't be contacted, I hope that they would do the best for him anyway, as he is in the hospital under your care".

*Communication rather than consent*

Three respondents commented on the importance of communication about procedures, rather than a formal consent process. Two respondents wanted more information about procedures, for example, "I think more information needs to be told to family members. I think the doctors need to contact the next of kin and explain the procedures more to them".

*Satisfaction with care*

Eight respondents commented that they were happy with their care in ICU and three reported satisfaction with communication from the ICU team.

**Discussion**

ICU patients and NoK are unaware of many procedures performed during the ICU admission. Although our study did not audit procedural consent rates, this rate of awareness likely reflects a low rate of informed consent for

procedures and poor recall of information about procedures. This has medicolegal implications, with a risk of complications occurring from a procedure that the patient and their relatives were unaware had occurred.

Despite this, patients and NoK reported good satisfaction with the information they received regarding procedures. This suggests that there is not a strong impetus from patients and families to receive more information about ICU procedures. It may also reflect general satisfaction with ICU care, as several participants commented on quality of care rather than the specific issue of procedural consent.

Patients and NoK prefer verbal over written information, which is consistent with previous findings that verbal information is the most effective way of improving patient understanding.<sup>17</sup> There is certainly a role for written information, as it can be referred to over time, but this should be presented alongside verbal explanations.

Most respondents expected informed consent only before "risky or non-routine" procedures. This is an ambiguous phrase, as "routine" suggests that a procedure is low-risk when this is not necessarily the case. Conversely, all invasive procedures have some risks, and are therefore "risky". However, this option captured the ideas that some invasive procedures are more risky than others, and that respondents may not want to give consent to every procedure.

This leads to the difficult question, "Which procedures are risky or non-routine?" Some procedures may appear low-risk due to patient familiarity, for example intravenous cannula insertion, but the patient may simply be unaware of, or inured to, the risks of this common procedure. Our survey instrument allowed respondents to nominate specific procedures for which they would expect consent, but no respondent gave a list. This suggests that patients and families rely on the guidance of clinicians for which procedures require consent.

Doctors' expectations of which procedures require informed consent are not always based on the risks of the procedure and often appear arbitrary.<sup>1,5</sup> For example more doctors believe that informed consent should be obtained before bronchoscopy than endotracheal intubation.<sup>1</sup> Similarly, the attitudes of patients and NoK may be based on their familiarity with, or the discomfort of, a procedure rather than longer-term risks. A structured interview study may better draw out nuanced opinion on this complex issue.

The finding that only 27% of respondents expect consent before every procedure suggests there is not a strong push from ICU patients and NoK for mandatory procedural consent. Moreover, nearly 20% of patient respondents did not expect any informed consent process. This is consistent with previous findings that some patients want very little involvement in decision making, preferring to defer decisions to their treating doctor.<sup>16,18-20</sup> In order to accommo-

date the varied preferences of ICU patients, a tiered procedural consent process could allow patients to opt in or opt out of more detailed information and involvement in decision making.

There are several limitations to our study. As a small, single-centre study, the findings may not be applicable to ICU patients in different centres or countries. Our hospital is not a trauma centre, therefore trauma patients (a younger population needing multiple procedures) were not represented. Planned postoperative patients were excluded, but these patients potentially have an opportunity to discuss ICU procedures and care at a preoperative clinic. Whether this option appeals to patients is an area for further research. Finally, patients and NoK who did not speak English were excluded. Their views would be particularly valuable as they may have different expectations of medical decision making and consent.

The survey response rate was modest (53%), leading to potential selection bias and limiting the generalisability of our findings. Eligible non-participants had a higher mean APACHE score than participants, indicating a sampling bias with the study sample being less unwell than the source population. Obtaining informed consent to participate in the study may have favoured recruitment of participants who support informed consent. The difficulties we encountered in recruiting participants, eg, contacting NoK, may anticipate similar difficulties in obtaining consent for procedures.

## Conclusion

Participants in this study had a poor awareness of procedures performed during the patient's ICU admission. Most patients and families expected an informed consent process for some, but not all, ICU procedures. Most respondents preferred verbal information about procedures. There are no significant differences in the expectations of ICU patients and NoK regarding procedural consent in the ICU.

The expectations of ICU patients and their relatives are not the only relevant consideration when evaluating procedural consent, but they are certainly important. Therefore, our findings could be used to guide changes to ICU procedural consent processes in Australia. In particular, any procedural consent process should incorporate a verbal explanation of the procedure. A tiered consent system that allows patients and NoK to determine the extent of their involvement in decision making could accommodate the varied preferences found in this study.

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**Competing interests**

None declared.

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**References**

- 1 Stuke L, Jennings A, Gunst M, et al. Universal consent practice in academic intensive care units (ICUs). *J Intensive Care Med* 2010; 25: 46-52.
- 2 Davis N, Pohlman A, Gehlbach B, et al. Improving the process of informed consent in the critically ill. *JAMA* 2003; 289: 1963-8.
- 3 Marsillio LE, Morris MC. Informed consent for bedside procedures in the pediatric intensive care unit: a preliminary report. *Pediatr Crit Care Med* 2011; 12: e266-70.
- 4 College of Intensive Care Medicine of Australia and New Zealand. Statement on the ethical practice of intensive care medicine. Republished 2010. [http://www.cicm.org.au/cms\\_files/IC-9%20Statement%20on%20the%20Ethical%20Practice%20of%20Intensive%20Care%20Medicine.pdf](http://www.cicm.org.au/cms_files/IC-9%20Statement%20on%20the%20Ethical%20Practice%20of%20Intensive%20Care%20Medicine.pdf) (accessed Mar 2014).
- 5 Vincent JL. Information in the ICU: are we being honest with our patients? The results of a European questionnaire. *Intensive Care Med* 1998; 24: 1251-6.
- 6 Manthous CA, DeGirolamo A, Haddad C, Amoateng-Adjepong Y. Informed consent for medical procedures: local and national practices. *Chest* 2003; 124: 1978-84.
- 7 Modra LJ, Hilton A, Hart GK. Informed consent for procedures in the intensive care unit: ethical and practical considerations. *Crit Care Resusc* 2014; 16: 143-8.
- 8 Beauchamp TL, Childress JF. Principles of biomedical ethics. 6th ed. New York: Oxford University Press, 2008.
- 9 Sugarman J, McCrory DC, Powell D, et al. Empirical research on informed consent. An annotated bibliography. *Hastings Cent Rep* 1999; 29: S1-42.
- 10 Chenaud C, Merlani P, Ricou B. Informed consent for research in ICU obtained before ICU admission. *Intensive Care Med* 2006; 32: 439-44.
- 11 Astley CM, Chew DP, Aylward PE, et al. A randomised study of three different informational AIDS prior to coronary angiography, measuring patient recall, satisfaction and anxiety. *Heart Lung Circ* 2008; 17: 25-32.
- 12 Larobina ME, Merry CJ, Negri JC, Pick AW. Is informed consent in cardiac surgery and percutaneous coronary intervention achievable? *ANZ J Surg* 2007; 77: 530-4.
- 13 World Health Organization. Surgical safety checklist. 1st ed. [http://www.who.int/patientsafety/safesurgery/tools\\_resources/SSSL\\_Checklist\\_finalJun08.pdf](http://www.who.int/patientsafety/safesurgery/tools_resources/SSSL_Checklist_finalJun08.pdf) (accessed Mar 2014).
- 14 Douglas CD, McPhee JR. Informed consent: a review of the ethical and legal basis for medical decision-making for the competent patient. *ANZ J Surg* 2007; 77: 521-2.
- 15 Clark PA. Intensive care patients' evaluations of the informed consent process. *Dimens Crit Care Nurs* 2007; 26: 207-26.
- 16 Davis MA, Hoffman JR, Hsu J. Impact of patient acuity on preference for information and autonomy in decision making. *Acad Emerg Med* 1999; 6: 781-5.
- 17 Flory J, Emanuel E. Interventions to improve research participants' understanding in informed consent for research: a systematic review. *JAMA* 2004; 292: 1593-601.
- 18 Curtis JR, Tonelli MR. Shared decision-making in the ICU: value, challenges, and limitations. *Am J Respir Crit Care Med* 2011; 183: 840-1.
- 19 Beresford N, Seymour L, Vincent C, Moat N. Risks of elective cardiac surgery: what do patients want to know? *Heart* 2001; 86: 626-31.
- 20 Ivarsson B, Larsson S, Lühns C, Sjöberg T. Extended written pre-operative information about possible complications at cardiac surgery — do the patients want to know? *Eur J Cardiothorac Surg* 2005; 28: 407-14. □

## NEXT OF KIN SURVEY: INFORMED CONSENT FOR PROCEDURES IN THE ICU

This survey asks your opinion giving informed consent for procedures in the ICU.

By 'informed consent', we mean agreeing to or refusing a procedure after receiving information about it. By 'procedure', we mean inserting a needle, tube or instrument into the body to diagnose or treat an illness.

### 1. What is the name of your relative/friend who is a patient in the Intensive Care Unit?

### 2. What is your relationship to the patient?

### 3. What is your gender?

- Male
- Female

### 4. What is your age?

### 5. What is the main language you speak at home?

- English
- Other (please specify)

### 6. In which language would you prefer to receive information about ICU procedures?

- English
- Other (please specify)



**7. Which of the following procedures did your relative/friend have? You may tick more than one box.**

- Central venous catheter (neck line or groin line)
- Arterial line (art line)
- Vascath (line for kidney machine)
- Pulmonary Arterial Catheters (Swan-Ganz catheter, Swan)
- Endotracheal Intubation (breathing tube)
- Abdominal paracentesis (abdominal fluid tap)
- Intercostal catheter (chest tube)
- Lumbar puncture (spinal tap)
- Bronchoscopy (telescope into lungs)
- Gastroscopy (telescope into stomach)
- Urinary catheter (bladder tube)
- Rectal tube (flexiseal)
- Intravenous cannula (IV, drip)
- Nasogastric tube (feeding tube)
- I am unsure which procedures were performed during my admission to the intensive care unit.

Comment

## 8. Procedures actually performed

- Central venous catheter (neck line or groin line)
- Arterial line (art line)
- Vascath (line for kidney machine)
- Pulmonary Arterial Catheters (Swan-Ganz catheter, Swan)
- Endotracheal Intubation (breathing tube)
- Abdominal paracentesis (abdominal fluid tap)
- Intercostal catheter (chest tube)
- Lumbar puncture (spinal tap)
- Bronchoscopy (telescope into lungs)
- Gastroscopy (telescope into stomach)
- Urinary catheter (bladder tube)
- Rectal tube (flexiseal)
- Intravenous cannula (IV, drip)
- Nasogastric tube (feeding tube)

Comment

## 9. Procedures actually performed

	correctly identified	Unaware procedure performed	incorrectly thought procedure performed
Central venous catheter (neck line or groin line)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arterial line (art line)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vascath (line for kidney machine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary Arterial Catheters (Swan-Ganz catheter, Swan)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Endotracheal Intubation (breathing tube)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Abdominal paracentesis (abdominal fluid tap)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intercostal catheter (chest tube)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lumbar puncture (spinal tap)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bronchoscopy (telescope into lungs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gastroscopy (telescope into stomach)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Urinary catheter (bladder tube)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rectal tube (flexiseal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intravenous cannula (IV, drip)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nasogastric tube (feeding tube)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comment

**10. How were you informed about these procedures? You may tick more than one box.**

- A nurse spoke to me.
- A doctor spoke to me
- Another healthcare professional spoke to me (eg physiotherapist, dietitian, speech pathologist)
- My family member spoke to me
- I spoke to another patient or another patient's family
- I was given written information
- I looked it up on the internet
- I did NOT receive information about procedures
- Other (please specify)

**11. Which was the MOST useful source of information? Tick ONLY ONE box.**

- Nurse
- Doctor
- Other healthcare professional
- My family member
- Another patient's family member
- Written Information
- Internet
- Other (please specify)

**12. How would you prefer to receive information about procedures? Tick ONLY ONE box.**

- Written information
- Verbal information (for example talking with a doctor or nurse)
- Both written and verbal information
- I do not want information about procedures performed during my ICU admission
- Other (please specify)

**13. Do you agree with the following statements about your family member/friend's ICU admission?**

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I received enough information about procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information I received about procedures was easy to understand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to receive information about the progress of my family member's illness (getting better or getting worse)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important to receive information about procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**14. If your relative/friend is too unwell to answer for themselves, would you expect to be asked: (tick only one box)**

- Before every procedure
- Before procedures that are risky or not routine
- I don't expect to be asked for consent before procedures necessary for my family member/friend's treatment.
- Before some procedures (please list)

**15. How would you prefer to give your consent or permission for a procedure? Tick ONLY ONE box.**

- By signing a form
- By verbally consenting or refusing it (not signing a form)
- I do not want to be asked for consent.
- Other (please specify)

**16. Do you have any other comments about giving consent or permission for procedures performed in the ICU? (please comment below)**